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Change in psychological distress in longer-term oesophageal cancer carers: are clusters of illness perception change a useful determinant?

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Short form title: Distress and illness perceptions in oesophageal cancer carers

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Abstract

Objective: This study provides a longitudinal assessment of distress in longer-term oesophageal cancer carers, while examining illness perception schema as a possible determinant of change in distress over time.

Methods: Oesophageal cancer carers (n=171), 48-months post-diagnosis, were assessed at baseline and 12-months later with the Illness Perception Questionnaire-Revised, Cancer Coping Questionnaire, Hospital Anxiety and Depression Scale and Concerns About Recurrence Scale.

Results: Findings report deterioration from normal to probable anxiety in 35.7% of carers and probable depression in 28.7% carers over time. Fear of recurrence remained stable. Changes in control, consequence and cause beliefs were identified as key determinants of a change in psychological morbidity.

Conclusions: Illness beliefs appear to be valuable targets for psychological intervention to improve wellbeing among carers of people with oesophageal cancer.

Keywords: cancer; oncology; oesophagus; carers; anxiety; depression

Background

Despite widespread acknowledgement of cancer carers as "secondary survivors" reporting equivalent levels of psychological morbidity to survivors [1], there is a relative dearth of attention given to the psychological sequelae from caregiving [2;3]. This is an important gap in the literature, as carer stress is often considered to have an impact on patient outcomes [4]. Oesophageal cancer carers have received little research attention yet align to an increasingly prevalent survivor group [5]. Oesophageal cancer carers face a myriad of challenges typical of caring for survivors of a gastro-intestinal cancer, including a poor prognosis [6] and a significant, lasting impact on quality of life [7].

Levels of psychological morbidity in this carer population are largely unknown, with only two relevant studies [8;9]. One study demonstrated that 71% of carers would benefit from formal mental health care [8]; the other demonstrated 30% of carers report moderate/high levels of anxiety, 10% report moderate/high levels of depression, and significant levels of fear of recurrence [9]. Both studies are cross-sectional in design and, as with the majority of cancer carer research, involve people who have been carers for a relatively short time [10]. Longitudinal studies are needed to examine change in psychological distress so that supportive care needs may be met across the illness trajectory [11].

Possible key determinants of psychological distress in oesophageal cancer carers are illness perceptions, as conceptualised by Leventhal's Common-Sense Model [CSM;12]. Illness perceptions are the cognitive and emotional representations of illness held by an individual. The CSM suggests that an individual will attempt to assign meaning to an illness via their perceptions about the illness. In an effort to restore normal functioning, individuals will develop coping strategies (based on their illness perceptions), which will then be evaluated in terms of their success in restoring equilibrium. The result of this evaluation may be a change in coping strategy and/or a change in perceptions about the illness. In summary, the model suggests that a person's perceptions about an illness and their coping strategies can have an impact on their psychological well-being.

A previous cross-sectional study of oesophageal cancer carers reported that illness perceptions accounted for the majority of explained variance in anxiety, depression, and fear of recurrence [9]. Psychological distress was higher in carers who believe that (i) the illness is more acute and cyclical in pattern, (ii) the survivor has a poor understanding of their condition, and (iii) serious consequences await both the survivor and themselves.

Several illness perception interventions have shown promise in reducing psychological morbidity in carer populations [13;14]. Although previous research [9] is useful in identifying which illness perceptions are associated with psychological distress at one point in time, development of an intervention modifying illness perceptions requires evidence that a change in illness perceptions corresponds to a change in levels of psychological distress. The majority of longitudinal designs predict an outcome at follow-up from illness perceptions at baseline [15]. Studies moving beyond a prediction model have done so by identifying individuals sharing collections of illness beliefs which change in a similar way over time [16;17]. This method of studying illness perception 'schema' [18] has various benefits, not least the conceptual relevance to the CSM of studying a collection of beliefs as opposed to single illness perceptions in isolation. No other study has used cluster analysis to identify groups of carers sharing illness perception schema and provide a longitudinal assessment of psychological distress in this population.

The present research aims to: (i) provide a longitudinal assessment of anxiety, depression and fear of recurrence in longer-term oesophageal cancer carers and to (ii) determine if subgroups of oesophageal cancer carers share schema reporting similar change over time, and if these schema are useful in predicting change in psychological distress.

Methods

Oesophageal cancer survivors registered on the Oesophageal Patient's Association (OPA) database were invited, by post, to give a questionnaire pack to their carer, i.e. a partner/relative/friend they identified as being their main source of emotional and physical support. To be eligible to participate, the survivor needed to have undergone oesophagectomy for oesophageal cancer. A second identical questionnaire pack was mailed to the carers approximately 12 months later.

Ethical approval for the study was gained from the University Ethics Committee, Queen's University Belfast.

The questionnaire pack included the following measures –

Demographic and health related items - gender, age, relationship to survivor, geographic region, living arrangement, employment status, time since cancer diagnosis and whether or not the survivor had any comorbidities.

Anxiety and Depression – the 14-item Hospital Anxiety and Depression Scale [HADS;19] assesses levels of generalised anxiety and depression. Responses are on a Likert scale, higher scores indicating higher symptom frequencies (subscale range 0-21). The following scores indicate the degree to which a respondent might be a clinical 'case' [19]; normal (<8), possible (8-10) and probable clinical anxiety or depressive case (11-21). The HADS has been validated among clinical and non-clinical populations [20;21].

Fear of Recurrence – the 4-item Concerns About Recurrence Scale- Part 1 (CARS;22) assesses overall fear of recurrence; frequency, potential for upset, consistency and intensity of fears. Responses are given on a Likert scale from 1 to 6, with higher total scores indicating a greater fear of recurrence. The scale has good evidence for reliability and validity (23;24). Carers were asked about their fear of cancer recurrence for the survivor (Cronbach's alpha = 0.90).

Coping Strategies - the 21-item Cancer Coping Questionnaire [CCQ;25] assesses coping strategies used in the previous week: interpersonal support, reflection/relaxation coping, diversion, planning, and positive focus. Responses are on a 1-4 Likert scale. Higher scores indicate greater use of a coping strategy. There is good evidence for reliability and validity [25]. Carers were asked about how they cope with the survivor's cancer (Cronbach's alpha = 0.70 to 0.89).

Illness Perceptions – the Illness Perception Questionnaire-Revised [IPQ-R;26] measures a respondent's beliefs about illness: cause of illness, timeline acute or chronic, timeline cyclical or episodic, consequences of illness, personal control, treatment control and illness coherence. A modified version of the IPQ-R [27] is used to address the illness perceptions of personal control, consequences and illness coherence from the perspective of both the carer and survivor. Further information on the modifications made for carers has been reported previously [9, 28]. Responses are on a Likert scale (1 to 5), with higher scores representing stronger beliefs. To assess perceived cause, an open-ended item asks respondents to state the three main causes of the survivor's condition. Similar to previous research [9], the data on perceived causes from the current sample were subjected to factor analysis revealing three factors; emotional causes (e.g. stress), behavioural causes (e.g.

smoking), and external causes (e.g. fate), explaining 44% of the total variance. The IPQ-R has considerable evidence to support its reliability and validity, including among oesophageal cancer survivors [29]. In this study, Cronbach's alpha for the scales on the carer's version of the IPQ-R ranged from 0.77 to 0.90.

Statistical Analysis

Statistical analysis was conducted in SPSS (version 21).

Change scores were calculated by subtracting the second time point score from the first time point score. Cluster analysis was applied to the standardised IPQ-R change scores, to identify participants whose illness beliefs changed in a similar way. The two-stage method used is that of Milligan [30] identified by Clatworthy and colleagues [18] as being the optimum for illness perception research. Firstly a hierarchical cluster analysis (Ward's clustering method) was used to identify the number of clusters, with squared Euclidean distance as the similarity measure. By observing the dendrogram and the agglomeration schedule, three clusters were identified as emerging from the data. The stability of clusters was validated by dividing the study sample in half and repeating the cluster analysis on each, with a similar three cluster structure emerging. The number of clusters and cluster centroids identified using the Ward's method were then entered into an iterative cluster analysis (K-means clustering method). Differences between clusters were assessed using ANOVA to assess differences in change scores.

Separate hierarchical regression analyses were conducted to construct a model of change in anxiety, depression and fear of recurrence. Demographic and medical variables were entered in the first block, with CCQ change scores and IPQ-R cluster membership entered in the second block. Demographic variables with more than 2 levels and IPQ-R cluster membership were entered as dummy variables.

Results

Carer Characteristics

A total of 379 carers returned their questionnaires at baseline, with 228 carers returning the survey at both time-points (40% dropout rate over time) and after removing participants with missing data, complete data were provided by 171 carers. There was no significant difference

on depression (t=1.99, p=.05) or fear of recurrence (t=1.44, p=.152) between the participants who provided complete data at both time points and the participants who provided data at time 1 only. Non-completers were significantly more anxious than completers (t=2.54, p=.011), but the effect size was small (Cohen's d=0.26). The mean age of participants was 62.56 years (SD=10.05), predominantly female (72.5%) and retired (61.4%). The majority of participants were the survivor's spouse or partner (96.49%), and represented a longer term survivor population who at inclusion in the study were 4 years post-diagnosis on average (IQR = 2-7 years).

Do levels of psychological distress change over time in oesophageal cancer carers?

At baseline, carers reported a HADS Anxiety score of M=7.50 (SD=4.72) and a HADS Depression score of M=4.47 (SD = 3.82). At 12-month follow-up levels of anxiety M=14.44 (SD=4.84) and levels of depression M=11.41 (SD=3.99) had increased significantly, with a large effect size (anxiety d=1.45 and depression d=1.78) from baseline. Using the HADS clinical cut-off scores [19], 48.5% (83/171) of the carer sample deteriorated from normal levels of anxiety into possible or probable anxiety. With depression there was a similar marked deterioration, with 67.3% (115/171) of the carers reporting normal levels of depression at baseline and possible/probable depression at 12 months. No improvements from probable to normal levels of psychological morbidity were reported.

Levels of fear of recurrence as assessed by the CARS remained relatively stable over time with no significant difference between baseline M=13.65 (SD=5.58) and follow-up M=13.97, (SD=5.59).

Do subgroups of oesophageal cancer carers share illness perception 'schema' which report similar change over time?

Three distinct clusters emerged from the data. Mean difference scores are displayed in Table 1.

Cluster 1 (n=79) represents a group of carers who display a marginal to moderate change in beliefs over time, increasingly believing the illness to be more acute and with a cyclical presentation of symptoms, and to have more severe consequences (for themselves and the survivor). These carers have increasingly strong causal beliefs, particularly belief in an emotional cause.

Cluster 2 (n=26) represents a group of carers with most illness beliefs reporting a marked change over time. These carers report belief in an increasingly chronic condition, with an episodic presentation of symptoms and a lessening of (carer/survivor/treatment) control. They increasingly believe that they and the survivor understand the condition, and feel over time that there will be less severe consequences for themselves and the survivor. Over time their causal beliefs weaken.

. Cluster 3 (n=66) represents a group of carers who report marginal to moderate change including a decreasing belief in severe consequences for survivor and carer, an increase in the perception that the condition is acute and with a cyclical presentation of symptoms, and who report a marked increase in all control beliefs. The carers also increasingly feel they and the survivor do not understand the condition, and feel less strongly about the cause of the condition over time.

There was a significant difference in change in anxiety between the three clusters (see Table 1). Carers in cluster 1 reported a mean increase in anxiety over time, with anxiety decreasing in carers in clusters 2 and 3. Similarly, there was a significant difference in change in depression between the three clusters. Carers in cluster 1 reported a mean increase in depression over time, with depression decreasing in carers in cluster 2 and 3. Cluster 1 and 2 were distinct from each other in relation to change in anxiety and depression, with cluster 3 not significantly different in relation to change in anxiety or depression from either of the other two clusters. There was no significant difference in relation to change in fear of recurrence (CARS) between clusters.

All three clusters were distinguishable on several illness perception domains, each displaying a significant large effect between clusters: Personal Control (Survivor), Personal Control (Carer), and Illness Coherence (Carer).

<u>Are illness perception clusters useful in predicting change in psychological distress over time?</u>

Fear of Recurrence

The covariates in the regression model explained a total of 16.3% of the variance in change in fear of recurrence, $F(7,145)=1.129$, $p=.004$. The first block (containing demographic and medical variables) accounted for 9.2% of variance in change FoR, with the second block

(containing change in use of coping strategies and cluster membership) accounting for a further 7.1% of variance.

There were several significant predictors in the model (see Table 2). Cluster membership was the most significant predictor, with cluster 3 associated with a decrease in fear of recurrence over time in comparison to cluster 1. An increase in the use of interpersonal coping over time was another significant predictor, associated with an increase in fear of recurrence over time. No demographic or medical variables significantly predicted changes in fear of recurrence.

Depression

The covariates in the regression model explained a total of 26.4% of the variance in change in depression, $F(7,145)=2.081$, $p=.004$. The first block of the model accounted for 13.2% of variance in change in depression, with the second block accounting for a further 13.2% of variance.

There were several significant predictors in the model (see Table 3). Cluster membership was the most significant predictor, with both cluster 2 and cluster 3 associated with a decrease in depressive symptomology over time in comparison to cluster 1. An increase in the use of positive focus over time was also a significant predictor of changes in depression levels, associated with a decrease in depression over time. No demographic or medical variables significantly predicted changes in depression.

Anxiety

The covariates in the regression model explained a total of 37.4% of the variance in anxiety change, $F(7,145)=3.466$, $p<.001$. The first block of the model accounted for 12.2% of variance in change in anxiety, with the second block accounting for a further 25.2%.

There were several significant predictors in the model (see Table 4). An increase in the use of diversionary coping was the most significant predictor followed by relaxation/reflection coping, both associated with an increase in anxiety levels over time. An increase in positive focus coping strategies was associated with a decrease in anxiety over time. Cluster membership, in addition to demographic and medical variables, failed to significantly predict changes in anxiety.

Discussion

This is the first study to provide a longitudinal assessment of psychological distress in oesophageal cancer carers over time. It has previously been established that this carer population experience significant levels of anxiety and depression [9]. This paper extends this knowledge further by demonstrating a concerning deterioration in the psychological wellbeing of longer-term carers (average 4 years post-diagnosis) across a one year time period.

In the cancer literature there is an inconsistent relationship between time and psychological distress [31], though distress of carers in a mixed-cancer sample has been reported to increase (between 6-months to 3-years post-diagnosis) to levels comparable to the current sample of oesophageal cancer carers [32]. However, there is a dearth of longitudinal assessment extending beyond 3 years post-diagnosis. Therefore, there is no similar research with which to compare the findings of the current sample. These findings do however align to a similar increase in distress in longer-term oesophageal cancer survivors [16], with an acknowledged relationship between distress in survivors and carers [31].

A regression model demonstrated that no demographic or medical variables were significant predictors of a change in psychological distress over time. Although previous cross-sectional research reported younger age to be associated with heightened anxiety and fear of recurrence [9], other factors appear to be responsible for fluctuations (deteriorations or improvements) in distress levels over time. Increasing positive focus appears to reduce anxiety and depression (which is not surprising). However, an increase in diversionary and relaxation coping styles is associated with an increase in anxiety. It might be that these coping strategies represent an aspect of avoidance, which might be beneficial in the short term, but ultimately does not address the underlying issue, so is likely to lead to longer-term anxiety. For fear of recurrence, the strongest predictor in the model was interpersonal coping. Carers who are more likely to engage in this type of coping are also more likely to report high levels of fear of recurrence. The finding suggests a need for carers to find alternative sources of social support as a coping mechanism, as they do not derive a benefit from seeking support from the oesophageal cancer survivor. This might be the result of putting the needs of the relative they care for above their own [33].

Cluster membership was found to be one of strongest covariates of change in fear of recurrence and change in depression over one year in longer-term carers. Three clusters emerged from the data. Cluster 1 represents *an increasingly pessimistic* group of carers, Cluster 2 represents *an increasingly realistic, yet powerless* group of carers and Cluster 3 represents *an increasing hopeful and in control* group of carers. These clusters represent meaningful sub-groups of helplessness/hopelessness, a dimension, which has been shown previously to be associated with distress [34]. Membership of clusters 2 and 3 was a significant predictor of reduction in depression over time. The distinguishable attribute from clusters 2 and 3 is a reduction in a belief of severe consequences for the survivor and carer over time, in addition to a reduction in causal beliefs. Membership of cluster 3 was a significant predictor of a reduction in fear of recurrence over time. The distinguishable attribute was an increase in control beliefs over time. In summary, it would appear beneficial to target the illness beliefs of consequences, cause and control in any prospective intervention.

There are several limitations with the current study**.** Firstly, most of the questionnaires were originally designed to be used with patients rather than carers. Although these questionnaires have been used previously with carers of oesophageal cancer survivors [9, 28] and show good levels of internal consistency in the current study, additional validation work with carer samples would be beneficial. Furthermore, there is some concern about whether the HADS measures anxiety and depression separately or general distress [35,36]. Secondly, illness perception clusters and coping strategies may be interpreted as explaining little variance in change in psychological distress. However, cluster membership was a better predictor of change in psychological distress than any medical or demographic variable and the levels of explained variance in psychological distress have occurred despite illness perceptions appearing to remain stable. Future research may measure change in illness perceptions and corresponding change in psychological distress over a more acute period (i.e. after diagnosis and through initial treatment). Finally, it is not possible to discern, from the current research, whether the change in coping or illness perceptions preceded the change in the outcome variables. Therefore, evidence is still needed that the active modification of illness beliefs is i) possible, and ii) will result in a change in psychological morbidity. A prospective intervention would provide this evidence.

In conclusion, the present study has reported that psychological wellbeing in a sizeable proportion of longer-term oesophageal cancer carers deteriorates over the course of a year. Illness perception schema have been identified as a key determinant of this change, with enhancing control beliefs, lessening focus on illness cause, and setting realistic expectations for consequences key elements for a prospective intervention.

Conflict of Interest Statement

None of the authors have any conflicts of interest to report.

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Table 1. Difference between cluster membership on standardised change scores

	Mean Difference Scores (SD)			F	p	Effect sizes for between group differences (Cohen's d)		
	Cluster 1 n=79	Cluster 2 n=26	Cluster 3 n=66			1&2	1&3	2&3
HADS-Anxiety	0.25 (0.85)	-0.40 (0.81)	-0.14 (1.15)	5.512	.005	-0.77**	-0.39	0.24
HADS-Depression	0.23 (0.92)	-0.37 (0.90)	-0.13 (1.08)	4.617	.011	-0.66*	-0.36	0.23
Fear of Recurrence	0.15 (1.01)	0.09 (0.89)	-0.22 (1.01)	2.573	.079			
CCQ-Reflection/ relaxation	0.21 (0.97)	-0.29 (0.98)	-0.14 (1.01)	3.688	.027			
CCQ-Positive focus	-0.09 (0.99)	0.01 (1.32)	0.11 (0.96)	.710	.493			
CCQ-Diversion	0.07 (0.88)	-0.10 (1.26)	-0.05 (1.03)	.400	.671			
CCQ-Planning	0.08 (1.05)	0.01 (0.98)	-0.10 (0.96)	.580	.561			
CCQ-Interpersonal	0.09 (1.06)	-0.35 (0.71)	0.03 (1.00)	2.001	.138			
IPQ-Acute/chronic timeline	0.05 (0.98)	0.46 (0.63)	-0.24 (1.08)	5.046	.007	0.46*	-0.29	-0.72**
IPQ-Cyclical timeline	0.14 (1.03)	-0.75 (0.71)	0.12 (0.94)	9.366	<.001	-0.92***	-0.02	0.99***
IPQ-Treatment control	-0.15 (0.86)	-0.61 (1.29)	0.43 (0.85)	13.556	<.001	-0.468	0.677***	1.048**
IPQ-Emotional cause	0.60 (0.88)	-0.26 (0.92)	-0.62 (0.71)	40.510	<.001	-0.97***	-1.51***	-0.46
IPQ-Behavioural cause	0.43 (0.97)	-0.13 (0.80)	-0.47 (0.88)	17.785	<.001	-0.61*	-0.97***	-0.39
IPQ-Externalised cause	0.47 (0.76)	-0.31 (0.87)	-0.44 (1.06)	20.078	<.001	-0.98**	-1.00***	-0.13
IPQ-Consequences for Patient	0.30 (0.81)	-0.29 (0.76)	-0.25 (1.18)	7.261	.001	-0.75**	-0.55**	-0.04
IPQ-Consequences for Carer	0.29 (1.02)	-0.21 (0.85)	-0.26 (0.95)	6.360	.002	-0.51*	-0.55**	-0.05
IPQ-Personal control of Patient	-0.07 (0.87)	-1.11 (0.72)	0.53 (0.85)	35.837	<.001	-1.24***	0.70***	2.01***
IPQ-Personal control of Carer	-0.15 (0.75)	-0.85 (1.19)	0.51 (0.90)	24.067	<.001	-0.81*	0.80***	1.38***
IPQ-Illness coherence of Patient	-0.14 (0.87)	0.70 (1.35)	-0.11 (0.88)	8.222	<.001	0.83*	-0.01	-0.82*
IPQ-Illness coherence of Carer	-0.47 (0.91)	1.13 (0.84)	0.11 (0.74)	36.132	<.001	1.78***	0.69***	-1.32***

Bonferroni correction applied to significance values for ANOVA at 0.05 level.

Effect size is d Cohen's, adjusted for varied sample sizes

* p<0.05, ** p<0.01, *** p<0.001

Table 2. Regression analysis with change in fear of recurrence as the outcome variable

	Unstandardized regression coefficient	**t**	**p**	**Standardized regression coefficient**
Age	-.005	0.424	.672	-.053
Gender	-.058	-.297	.767	-.026
Number of months since diagnosis	-.001	-.715	.476	-.059
Other illnesses or medical conditions	-.179	-1.123	.263	-.090
CCQ-Planning	-.052	-.510	.611	-.052
CCQ-Interpersonal	.218	2.326	.021	.218
CCQ-Relaxation	.003	.028	.978	.003
CCQ-Positive focus	-.010	-.105	.916	-.010
CCQ-Diversionary	-.051	-.518	.605	-.051
IPQR-Cluster 2 versus Cluster 1	.022	.093	.926	.008
IPQR-Cluster 3 versus Cluster 1	-.419	-2.282	.024	-.205
Constant	.759	.819	.414	

Step 1 R^2 =.092, R^2 *adj* =-.016. Step 2 R^2 =.163, R^2 *adj* =.019

Table 3. Regression analysis with change in depression as the outcome variable

	Unstandardized regression coefficient	**t**	**p**	**Standardized regression coefficient**
Age	-.010	-.840	.402	-.099
Gender	-.043	-.235	.814	-.019
Number of months since diagnosis	.00009449	.061	.952	.005
Other illnesses or medical conditions	-.161	-1.079	.282	-.081
CCQ-Planning	.169	1.785	.076	.169
CCQ-Interpersonal	.128	1.454	.148	.128
CCQ-Relaxation	-.049	-.505	.614	-.049
CCQ-Positive focus	-.243	-2.802	.006	-.243
CCQ-Diversionary	.101	1.081	.281	.101
IPQR-Cluster 2 versus Cluster 1	-.494	-2.197	.030	-.178
IPQR-Cluster 3 versus Cluster 1	-.375	-2.177	.031	-.183
Constant	.960	1.106	.270	

Step 1 R^2=.132, R^2 *adj*=.029. Step 2 R^2=.264, R^2*adj*=.137

Table 4. Regression analysis with change in anxiety as the outcome variable

	Unstandardized regression coefficient	**t**	**p**	**Standardized regression coefficient**
Age	-.021	-1.919	.057	-.208
Gender	-.323	-1.931	.055	-.145
Number of months since diagnosis	.000	.145	.885	.010
Other illnesses or medical conditions	-.108	-.782	.436	-.054
CCQ-Planning	-.048	-.552	.582	-.048
CCQ-Interpersonal	.128	1.578	.117	.128
CCQ-Relaxation	.234	2.613	.010	.234
CCQ-Positive focus	-.173	-2.163	.032	-.173
CCQ-Diversionary	.283	3.301	.001	.283
IPQR-Cluster 2 versus Cluster 1	-.397	-1.912	0.58	-.143
IPQR-Cluster 3 versus Cluster 1	-.298	-1.878	.062	-.146
Constant	1.782		2.225	.028

Step 1 R^2 =.122, R^2 *adj* =.018. Step 2 R^2=.374, R^2 *adj* =.266